# Rare Diseases and Scientific Inquiry

developed under a contract from the
National Institutes of Health

Office of Rare Diseases Research


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Please contact the NIH Office of Science Education with questions about this supplement at supplements@science.education.nih.gov.

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# Foreword

*Rare Diseases and Scientific Inquiry* is the most recent addition to the National Institutes of Health (NIH) Curriculum Supplement Series. This series brings the latest medical science and research discoveries from NIH into the K–12 classroom. NIH plays a vital role in the health of all Americans and seeks to foster interest in research, science, and medicine-related careers for future generations. The NIH Office of Science Education is dedicated to promoting scientific literacy and the knowledge and skills we need to secure a healthy future for all.

*Rare Diseases and Scientific Inquiry* gives students an opportunity to grapple with some of the most challenging and engaging medical issues that confront our society. We designed *Rare Diseases and Scientific Inquiry* to complement existing life science curricula and to be consistent with *National Science Education Standards*. Middle school science teachers, medical experts, education specialists, scientists, representatives from the NIH Office of Rare Diseases Research (ORDR), and curriculum-design experts from Biological Sciences Curriculum Study (BSCS) created the activities. The collaborative development process includes geographically dispersed field tests by teachers and students.

The curriculum supplements enable teachers to facilitate learning and stimulate student interest by applying scientific concepts to real-life scenarios. Design elements emphasize key biology concepts and analytic methods, cutting-edge science content, and built-in assessment tools. Activities promote active and collaborative learning to help students develop problem-solving strategies and critical-thinking skills.

Each of our curriculum supplements comes with a complete set of printed materials for teachers, including extensive background and resource information, detailed lesson plans, and masters for student worksheets. The Web site accompanying *Rare Diseases and Scientific Inquiry* has interactive materials to support the lessons. The supplements are distributed for free to educators across the United States upon request. They may be copied for classroom use and educational purposes but may not be sold.

We welcome your feedback. For a complete list of curriculum supplements and ordering information, or to submit feedback, visit http://science.education.nih.gov or write to

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supplements@science.education.nih.gov

We appreciate the valuable contributions from the talented staff at BSCS. We are also grateful to the NIH scientists, advisors, and all other participating professionals for their work and dedication. Finally, we thank the teachers and students who participated in focus groups and field tests to ensure that these supplements are both engaging and effective. I hope you find our series a valuable addition to your classroom, and I wish you a productive school year.

Bruce A. Fuchs, Ph.D.
Director
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# About the National Institutes of Health

Founded in 1887, NIH is the federal focal point for health research in the United States. Today, it is one of the agencies in the Department of Health and Human Services. Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability. NIH works toward meeting the mission by providing leadership, direction, and grant support to programs designed to improve the health of the nation through research.

NIH's education programs contribute to ensuring the continued supply of well-trained basic research and clinical investigators, as well as the myriad professionals in many allied disciplines who support the research enterprise. These efforts also help educate people about scientific results so that they can make informed decisions about their own—and the public's—health.

This curriculum supplement is one such education effort. It is a collaboration among the Office of Rare Diseases Research, the NIH Office of Science Education, and Biological Sciences Curriculum Study.

For more about NIH, visit http://www.nih.gov.

# About the Office of Rare Diseases Research

The Office of Rare Diseases (ORD) was established in 1993 at the National Institutes of Health. Later, the ORD's focus on research prompted a name change to the Office of Rare Diseases Research (ORDR). The ORDR provides information on rare diseases and rare disease research; supports scientific conferences; cosponsors, with the National Human Genome Research Institute, the Genetic and Rare Diseases Information Center; and coordinates and supports research on the diagnosis and treatment of rare diseases both intramurally and extramurally. The Office also funds the Rare Diseases Clinical Research Network (RDCRN), a group of clinical research sites in the United States and several foreign countries working on about 100 different rare diseases, and is working to harmonize community efforts on patient registries and biospecimen repositories. A rare disease (also called an "orphan disease") is a condition affecting fewer than 200,000 people in the United States (about 1 in 1,500) or one affecting more people but "for which no reasonable expectation exists that the costs of developing or distributing a drug can be recovered from the sale of the drug in the United States" (Orphan Drug Act of 1983).

For more about the ORDR, visit http://rarediseases.info.nih.gov.

# About Biological Sciences Curriculum Study

Headquartered in Colorado Springs, Colorado, BSCS was founded in 1958 as a curriculum study committed to an evidence- and inquiry-based approach to science education. BSCS instructional materials and professional development services are based on current research about teaching and learning for all science classrooms, kindergarten through college.

BSCS's materials are extensively field-tested in diverse settings across the country and evaluated for proven effectiveness. The BSCS 5E Instructional Model and inquiry are hallmarks of its materials, placing students at the center of their learning.

The BSCS mission is to transform science teaching and learning through research and development that strengthens learning environments and inspires a global community of scientifically literate citizens. BSCS is a 501(c)(3) nonprofit organization.

For more information, please visit http://www.bscs.org.